DOCUMENT RESUME

ED 248 621 EC 170 085

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TITLE Someday I May Want to Know about...Parent and Professional Communication: How to Give More and Get More.
INSTITUTION Montgomery County Association for Retarded Citizens, Rockville, MD.
PUB DATE 84
NOTE 7p.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Communication Skills; *Disabilities; Elementary Secondary Education; *Parent Participation; *Parent Role; *Parent Teacher Cooperation

ABSTRACT

Intended primarily for parents of and professionals working with handicapped children, the paper examines the parent-professional relationship and suggests ways to enhance communication. The parent's principal responsibility for monitoring the child's physical, psychological, and educational well-being is stressed. Suggestions for improving parent-professional cooperation are directed to professionals, including providing practical management ideas to parents, becoming aware of community resources, writing reports in understandable language and giving parents copies of those reports, helping parents to think of life with this child in the same terms as life with other children, and making sure that parents understand the child's abilities as well as disabilities. Suggestions addressed to parents include insisting on their rights to consultation in every step of diagnosis and placement, becoming skilled in persuasion, enlisting one person's help in coordinating diagnostic visits and results, learning to keep comprehensive records, and learning as much as possible about the child's problem. (CL)

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Someday I may want to know about....

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Parent and Professional Communication:

How to Give More and Get More

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A MCARC INFORMATION SHEET

prepared by Kathryn (Peg) Morton, Former Director
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984-5792

One in a series on subjects of interest to parents and others concerned with the well-being of children and adults who are mentally retarded.

Reprinted 1984

EC170085

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In the course of raising a handicapped child most parents will encounter a large number of many kinds of professionals--physicians, psychologists, teachers, etc. Some will be helpful and others will not. Likewise, professionals whose trade is the handicapped child will encounter a large number and many kinds of parents. Some will be informed, cooperative, and helpful; others will not. It seems safe to wager, however, that the quality and quantity of help and support the child receives will hinge on the ability of the parent and professional to deal effectively with each other. Parents are generally the people who know their child best and the professional should respect and utilize that knowledge. The professional is generally expert in his speciality. It should be part of his obligation to communicate his insights and information to the parent. And both should keep in mind that it is the parent who must shepherd his child through the array of services he will need in the process of growing up. The more information and understanding the parent gets from the professional, the better the job he will do.

This is the era of the team approach in diagnosing and program planning for handicapped children. In some settings, such as hospitals, institutions, and schools, various professionals meet together and share information about the child, each from his own discipline's perspective. In many cases, parents are invited to be part of the team and meet with the professionals. When they do, they should certainly consider themselves experts among experts.

But the gathering together of all the professionals who influence the child's health care, education, and home life is obviously impossible outside of such settings. Johnny has a pediatrician; he also has a teacher; in addition, he may be receiving bi-weekly speech or physical therapy at a clinic; his family may be receiving the help of a public health nurse or a social worker. Someone must coordinate the various visits to and conversations with the several professionals who are helping the child. Often the primary physician serves as a coordinator, although his knowledge of what goes on in the child's classroom is usually limited to what the parent tells him. Practically speaking, the ultimate, ongoing responsibility for monitoring the child's physical, psychological, and educational well-being falls to the parent.

In the not-too-distant past, few parents considered themselves competent for the task. And even fewer professionals were willing to treat them as competent. Fortunately for all, the postures are definitely changing. More physicians, for instance, are declaring that the health of the patient is not the physician's responsibility. It is rather that of the patient and the community with the physician acting only as a consultant. A happy consequence of this new look is that a far larger share of the appointment hour is going towards "teaching" the patient about his condition--the reasons for diagnosis, what changes to watch for, etc. Parents are changing, too. They are far more confident of their abilities to participate in the diagnostic or decision-making processes and far less awed by professionals.

The following set of "Suggestions for Professionals and Parents" taken from Nicholas Hobbs' The Futures of Children* and still pertinent today is based on the assumption that the parents are the monitors and coordinators of their child's journey through the service system and that parents and professionals are capable of changing traditional patterns of behavior in dealing with each other.

Suggestions for Professionals

1. Have the parent(s) involved every step of the way. The dialogue established may be the most important thing you accomplish. If the parent's presence is an obstacle to testing because the child will not "cooperate" in his presence, the set-up should include a complete review of the testing procedure with the parent. (Remote video viewing or one-way windows are great if you are richly endowed.)

2. Make a realistic management plan part and parcel of the assessment outcome. Give the parents suggestions for how to live with the problem on a day-to-day basis, with the needs of the child, the capacities of the family, and the resources of the community all considered. Let the parents know that you will suggest modifications if any aspect of the management plan does not work.

3. Inform yourself about community resources. Give the parents advice on how to go about getting what they need. Steer them to the local parent organization.

4. Wherever possible, make the parent a team member in the actual diagnostic, treatment, or educational procedures. It will give you a chance to observe how the parent and child interact.

5. Write your reports in clear, understandable, jargon-free language. Professional terminology is a useful shortcut for your own note-taking; and you can always use it to communicate with others of your discipline. But in situations involving the parent, it operates as an obstacle to understanding. Keep in mind that it is the parent who must live with the child, help him along, shop for services to meet his needs, support his ego, give him guidance. You cannot be there to do it for him, so the parent must be as well informed as you can make him. Information that he does not understand is not useful to him. The goal is to "produce" a parent who understands his child well enough to help him handle his problem as he grows up.

6. Give copies of the reports to parents. They will need them to digest and understand the information in them; to share the information with other people close to the child; and to avoid the weeks or months of record-gathering which every application to a new program in the future will otherwise entail.

7. Be sure the parent understands that there is no such thing as a one-shot, final, and unchanging diagnosis. Make sure he understands that whatever label you give his child (if a label must be given) is merely a

* Nicholas Hobbs, The Futures of Children, Jossey-Bass, Inc., 1974, pp. 284-288.

device for communicating and one which may have all kinds of repercussions, many of them undesirable. Make sure he understands that it says very little about the child at present and even less about the child of the future. Caution him about using that label to "explain" his child's condition to other people.

8. Help the parent to think of life with this child in the same terms as life with his other children. It is an ongoing, problem-solving process. Assure him that he is capable of that problem solving and that you will be there to help him with it.

9. Be sure that he understands his child's abilities and assets as well as his disabilities and deficiences. What the child can do is far more important than what he cannot do, and the parent's goal thereafter is to look for new abilities and to welcome them with joy when they appear. Urge him to be honest and plain speaking with his child. Tell him that the most important job he has is to respect his child, as well as love him, and to help him "feel good about himself." Tell him that blame, either self-blame or blame of the child, has no part in the scene. It is no one's fault.

10. Warn the parent about service insufficiencies. Equip him with advice on how to make his way through the system of "helping" services. Warn him that they are not always helpful. Tell him that his child has a right to services. Tell him to insist on being a part of any decision making done about his child.

11. Explain to him that some people with whom he talks (teachers, doctors, professionals of any kind, other parents) may dwell on negatives. Help train the parent not only to think in positives but to teach other people important in his child's life to think in positives.

Suggestions for Parents

1. You are the primary helper, monitor, coordinator, observer, record-keeper, and decision-maker for your child. Insist that you be treated as such. It is your right to understand your child's diagnosis and the reasons for treatment recommendations, and for educational placement. No changes in his treatment or educational placement should take place without previous consultation with you.

2. Your success in getting as well informed as you will need to be in order to monitor your child's progress depends on your ability to work with the people who work with your child. You may encounter resistance to the idea of including you in the various diagnostic and decision-making processes. The way you handle that resistance is important. Your best tool is not the angry approach. Some of your job will include the gentler art of persuasion. Stay

confident and cool about your own abilities and intuitions. You know your child better than anyone else could. You are, obviously, a vital member of the team of experts.

3. Try to find, from among the many people whom you see, a person who can help you coordinate the various diagnostic visits and results. Pick the person with whom you have the best relationship, someone who understands your role as the principal monitor of your child's progress throughout life and who will help you become a good one.

4. Learn to keep records. As soon as you know that you have a child with a problem, start a notebook. Make entries of names, addresses, phone numbers, dates of visits, the persons present during the visits, and as much of what was said as you can remember. Record the questions you asked and the answers you received. Record any recommendations made. Make records of phone calls too; include the dates, the purpose, the result. It is best to make important requests by letter. Keep a copy for your notebook. Such documentation for every step of your efforts to get your child the service he needs can be the evidence which finally persuades a program director to give him what he needs. Without concise records of whom you spoke to, when you spoke to him, what he promised, how long you waited between the request and the response, you will be handicapped. No one can ever be held accountable for conversations or meetings with persons whose names and titles you do not remember, on dates you cannot recall, about topics which you cannot clearly discuss.

5. Make sure that you understand the terminology used by the professional. Ask him to translate his terms into lay language. Ask him to give examples of what he means. Do not leave his office until you are sure you understand what he has said so well that you can carry the information to your child's teacher, for instance, and explain it to her in clear, understandable language. (Write down the professional terms, too. Knowing them might come in handy some time.)

6. Ask for copies of your child's records. ... You could [also suggest] that a tape recording be made of any "interpretive" conference. It is very hard to remember what you said in such conferences.

7. Read. Learn as much as you can about your child's problem. But do not swallow whole what you read. Books are like people. They might be offering only one side of the story.

8. Talk freely and openly with as many professionals as you can bump into. Talk with other parents. Join a parent organization. By talking with people who "have been through it already," you can gain a perspective on your particular problems. Besides, you will receive moral support and will not feel quite so alone. Get information from parent organizations about services available, about their quality. But bear in mind that a particular program

might not help your child even though it has proved helpful for another child. Visit programs if you have the time and energy to do so. There is no substitute for firsthand views.

9. Stay in close touch with your child's teacher. Make sure you know what she is doing in the classroom so that, with her help, you can follow through at home. Share what you have read with her. Ask her for advice and suggestions. Get across the idea that the two of you are a team, working for the same goals. Make your child a part of that team whenever possible. He might have some great ideas.

10. Listen to your child. It is <u>his</u> point of view that he is giving you, and on that he is an expert.

11. Work hard at living the idea that different is just fine--not bad. Your child will learn from your example. Help him to think of problems as things that can be solved if people work at them together.

In the educational arena, educational advocacy courses can help parents and professionals understand their rights and responsibilities under federal law and local school policies.

MCARC's <u>Project TEAM</u> is one such course. Call 984-5792 for the dates and details of the next series.